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AUTHOR Scanlon, Robert G.
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ABSTRACT

Four major pieces of legislation enacted since 1974--Family Educational Rights and Privacy Act (the "Buckley Amendment"), Amendment to the Freedom of Information Act, The National Research Act, and The Privacy Act--represent a broad scope, impacting the administration of research, funding procedures, and the very substance and techniques of research. The legislation affects sampling, instrumentation, research design, data processing, data dissemination, and the retention of data. Thus, an entire research project has become subject to federal strictures. (Author/MLP)

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PRIVACY LEGISLATION

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ROBERT G. SCANLON
EXECUTIVE DIRECTOR
RESEARCH FOR BETTER SCHOOLS, INC.
1700 MARKET STREET
PHILADELPHIA, PA 19103

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PRIVACY LEGISLATION

THE INDIVIDUAL CITIZEN'S RIGHT TO PRIVACY AND FREEDOM OF INFORMATION HAS BECOME A MAJOR CONCERN IN THE PAST DECADE. MAJOR ACTIONS TAKEN BY THE FEDERAL GOVERNMENT IN THIS AREA INCLUDE FOUR MAJOR PIECES OF LEGISLATION AND RELATED REGULATIONS:

- FAMILY EDUCATIONAL RIGHTS AND PRIVACY ACT (THE "BUCKLEY AMENDMENT")
- AMENDMENT TO THE FREEDOM OF INFORMATION ACT
- THE PRIVACY ACT
- THE NATIONAL RESEARCH ACT

THESE STATUTES REPRESENT A BROAD SCOPE, IMPACTING THE ADMINISTRATION OF RESEARCH, FUNDING PROCEDURES, AND THE VERY SUBSTANCE AND TECHNIQUES OF RESEARCH. THE LEGISLATION AFFECTS SAMPLING, INSTRUMENTATION, RESEARCH DESIGN, DATA PROCESSING, DATA DISSEMINATION, AND THE RETENTION OF DATA. THUS, AN ENTIRE RESEARCH PROJECT HAS BECOME SUBJECT TO

FEDERAL STRICTURES. THE FOUR LAWS CITED ABOVE WILL NOW BE DISCUSSED IN MORE DETAIL.

THE BUCKLEY AMENDMENT, AS THE FAMILY EDUCATIONAL RIGHTS AND PRIVACY ACT OF 1974 IS COMMONLY KNOWN, PROTECTS THE PRIVACY OF STUDENTS' EDUCATIONAL RECORDS. THE MAJOR PROVISIONS OF THE ACT STATE THAT:

- a) PARENTS HAVE A RIGHT TO INSPECT AND REVIEW ALL OFFICIAL FILES, RECORDS AND DATA RELATING TO THEIR CHILDREN AND TO HAVE A HEARING TO CHALLENGE THE CONTENT OF THE RECORDS.
- b) DATA FROM SCHOOL RECORDS MANY NOT BE MADE AVAILABLE IN A PERSONALLY IDENTIFIABLE MANNER IN MOST CASES UNLESS THERE IS WRITTEN CONSENT OF THE PARENTS.
- c) PERSONAL INFORMATION WILL ONLY BE TRANSFERRED TO A THIRD PARTY ON THE CONDITION THAT SUCH PARTY DOES NOT SHARE PERSONALLY

IDENTIFIABLE INFORMATION WITH ANY OTHER PARTY WITHOUT WRITTEN CONSENT OF THE PARENTS.

REGULATIONS WERE PUBLISHED IN 1976 DEALING WITH MEASURES SCHOOL ADMINISTRATORS MUST TAKE TO PROTECT STUDENTS' AND FAMILIES' PRIVACY WHEN GRANTING ACCESS TO RECORDS. A SECOND SET OF REGULATIONS WHICH WERE TO CONCERN RESEARCH HAVE NEVER BEEN DEVELOPED AND PUBLISHED.

THE SECOND LAW, THE FREEDOM OF INFORMATION ACT, WAS FIRST ENACTED IN 1966 AND AMENDED IN 1974. KNOWN AS THE PUBLIC'S PASSKEY TO INFORMATION, THE FOIA PROVIDES FOR THE RELEASE OF INFORMATION HELD BY THE FEDERAL GOVERNMENT TO THE PUBLIC TO THE GREATEST EXTENT POSSIBLE. THE LEGISLATIVE INTENT PROVIDES THAT THE FOIA BE CONSTRUED TO CREATE LIBERAL DISCLOSURE REQUIREMENTS, LIMITED ONLY BY SPECIFIC EXEMPTIONS THAT ARE TO BE NARROWLY DEFINED. THE

ACT MAKES DISCLOSURE THE RULE AND SECRECY
THE EXCEPTION.

THERE IS CONSIDERABLE UNCERTAINTY AS TO THE SCOPE OF THE EXEMPTIONS WITH REGARD TO RESEARCH. THE PROBLEM IS THAT RESEARCH ACTIVITIES DO NOT MESH READILY WITH THE CONCEPTUALIZATIONS UNDERGIRDING THE LEGISLATION. FOIA DOES PROVIDE THAT RESEARCH PROTOCOLS AND DESIGNS SUBMITTED TO DHEW IN RESPONSE TO AN RFP ARE AVAILABLE UNDER FOIA, WHETHER FUNDED OR NOT. THUS, FOIA PLACES AT THE DISPOSAL OF EDUCATIONAL RESEARCHERS A WEALTH OF INFORMATION ABOUT THE TECHNIQUES AND PROCEDURES USED IN A SPECIFIC PIECE OF RESEARCH, MAKING IT POSSIBLE TO SUBJECT FEDERALLY SPONSORED RESEARCH TO THE KIND OF SCRUTINY WHICH ACADEMICIANS NORMALLY GIVE THEIR PEERS' WORK.

THERE IS A QUESTION, HOWEVER, AS TO WHETHER FOIA WOULD REQUIRE THE DISSEMINATION OF RESEARCH DATA ON IDENTIFIABLE INDIVIDUALS, e. g., AN IDENTIFIED INDIVIDUAL'S BELIEFS, OPINIONS,

ETC. RESEARCH RECORDS, INCLUDING THE COMPLETED INSTRUMENTS THEMSELVES, ARE POTENTIALLY AVAILABLE UNDER FOIA, UNLESS THEIR RELEASE WOULD CONSTITUTE A "CLEARLY UNWARRANTED INVASION OF PERSONAL PRIVACY."

IT IS KNOWN, FOR EXAMPLE, THAT DATA OR REPORTS REQUESTED OF A FEDERAL AGENCY UNDER FOIA MUST BE RELEASED. IF THIS IS A FINAL REPORT OR AN EVALUATION STUDY OR AN INTERIM REPORT ON A SURVEY TO BE CONDUCTED, ALL INFORMATION IN THE HANDS OF THE FEDERAL AGENCY IS AVAILABLE TO THE PUBLIC ON REQUEST. THE MORAL HERE IS NOT TO TURN OVER TO THE FEDERAL AGENCY, BE IT NIE OR OE, PERSONALLY IDENTIFIABLE DATA UNLESS YOU PLAN FOR PUBLIC ACCESS TO IT.

HOWEVER, IDENTIFIABLE INFORMATION IN THE HANDS OF CONTRACTORS IS NOT COVERED BY FOIA. THE QUESTION REMAINS, HOWEVER, WHAT IF THE FUNDER WERE TO RECEIVE A REQUEST FOR IDENTIFIABLE INFORMATION IN THE HANDS OF A CONTRACTOR? THE

FUNDER HAS A RIGHT TO THE INFORMATION IF THEY WANT IT. HOWEVER, THEY SHOULD NOT REQUEST IT FROM THE CONTRACTOR. ONCE CONFIDENTIAL INFORMATION IS TURNED OVER TO ANY FEDERAL AGENCY IT MUST BE RELEASED TO THE PUBLIC IF REQUESTED AND DHEW, FOR EXAMPLE, COULD DO NOTHING BUT HARM RELATIONSHIPS BETWEEN CONTRACTORS AND SUBJECTS, BE THEY SCHOOLS, SCHOOL DISTRICTS OR STATE DEPARTMENTS OF EDUCATION.

THIS DELIMMA COULD BE SOLVED IF CONTRACTORS AND FEDERAL AGENCIES WOULD DEVELOP A STATEMENT TO BE PUT IN ALL CONTRACTS TO THE EFFECT THAT "INASMUCH AS BOTH PARTIES AGREE THAT THE AGENCY HAS NO NEED TO KNOW THE NAMES OF INDIVIDUALS OR AGENCIES INVOLVED IN THE RESEARCH, THE CONTRACTOR WILL MAINTAIN LOCKED FILES AND USE AGGREGATE DATA OR PSEUDONYMS IN REPORTS TO THE FUNDER." THE EXACT WORDING OF THIS STATEMENT MAY BE DIFFERENT IN VARIOUS CONTRACTS.

THE THIRD MAJOR LAW, THE PRIVACY ACT OF 1974, IS DESIGNED "TO PROVIDE CERTAIN SAFEGUARDS AGAINST AN INVASION OF PERSONAL PRIVACY BY FEDERAL AGENCIES..." BY REGULATING THE ESTABLISHMENT AND USE OF RECORDS ON IDENTIFIABLE INDIVIDUALS WHETHER FOR ADMINISTRATIVE OR RESEARCH PURPOSES. UNDER THE PRIVACY ACT OF 1975, DHEW MUST IDENTIFY AND PUBLISH RECORDS SYSTEMS, ASSURE THE CONFIDENTIALITY OF PERSONAL INFORMATION IN THOSE SYSTEMS, AND ALLOW ACCESS TO THOSE RECORDS BY AFFECTED INDIVIDUALS.

THE PRIVACY ACT SUBJECTS DATA COLLECTED FOR STATISTICAL PURPOSES TO THE SAME PROVISIONS AS DATA COLLECTED FOR ADMINISTRATIVE PURPOSES. THAT REQUIREMENT IS UNFORTUNATE BECAUSE EDUCATIONAL STUDIES ARE OFTEN VOLUNTARY AND, THEREFORE, DEPEND, IN LARGE MEASURE, ON THE CREDENCE GIVEN TO THE DATA COLLECTOR'S PLEDGE OF CONFIDENTIALITY. STRONG CONFIDENTIALITY MEASURES THAT PROTECT INDIVIDUAL PRIVACY ARE A NECESSARY AND INTEGRAL PART OF EDUCATIONAL RESEARCH.

UNDER THE PRIVACY ACT, THE PRIVACY PROTECTION STUDY COMMISSION WAS ESTABLISHED WITH WIDE POWERS TO STUDY PUBLIC AND PRIVATE DATA SYSTEMS FOR THE PURPOSE OF RECOMMENDING LEGISLATION AS IT MAY BE NECESSARY TO PROTECT THE PRIVACY OF INDIVIDUALS WHILE MEETING THE LEGITIMATE NEEDS OF GOVERNMENT AND SOCIETY FOR INFORMATION. THE COMMISSIONS HELD HEARINGS ON SUCH ISSUES AS PERSONAL DATA RECORD-KEEPING POLICIES AND PRACTICES IN EDUCATIONAL INSTITUTIONS. UNDER CONSIDERATION WERE THE PROTECTIONS AFFORDED PARENTS AND STUDENTS BY THE BUCKLEY AMENDMENT. RESULTING FROM THESE HEARINGS, AND OTHERS WERE A SET OF RECOMMENDATIONS TO THE PRESIDENT AND CONGRESS IN JULY 1977 ENTITLED PERSONAL PRIVACY IN AN INFORMATION SOCIETY. RECOMMENDATIONS OF THE COMMISSION ATTEMPT:

1. TO EXPAND AND STRENGTHEN FERPA'S MINIMUM REQUIREMENTS SO AS TO PLACE ADDITIONAL RESPONSIBILITY FOR THE QUALITY OF RECORDS AND RECORD-KEEPING PRACTICES ON EDUCATIONAL INSTITUTIONS, AND TO BROADEN THE SPECTRUM OF INSTITUTIONS AND RECORDS SUBJECT TO THE ACT'S REQUIREMENTS.

2. TO MAKE EDUCATIONAL INSTITUTIONS MORE ACCOUNTABLE FOR THEIR RECORD-KEEPING PRACTICES THAN THEY NOW ARE BY GIVING THE INDIVIDUAL EFFECTIVE REMEDIES FOR SPECIFIC ABUSES.
3. TO EXPAND THE LATITUDE OF EACH EDUCATIONAL INSTITUTION OR AGENCY IN MEETING ITS INCREASED RESPONSIBILITIES AND ADAPTING THE BASIC REQUIREMENTS OF FERPA TO LOCAL CIRCUMSTANCES WITHIN THE CONTEXT OF STRENGTHENED ACCOUNTABILITY.

THE "PROTECTION OF HUMAN SUBJECTS" REGULATIONS AND THE NATIONAL RESEARCH ACT OF 1974 WHICH AUTHORIZES THEM REQUIRE THE ESTABLISHMENT OF AN INSTITUTIONAL REVIEW BOARD TO REVIEW AND APPROVE ALL BIOMEDICAL AND BEHAVIOR RESEARCH ACTIVITIES INVOLVING HUMAN PARTICIPANTS. THE REVIEW IS TO DETERMINE THAT THE SUBJECT'S WELFARE AND RIGHTS ARE ADEQUATELY PROTECTED, THAT THE RISKS ARE OUTWEIGHED BY THE "POTENTIAL

BENEFITS TO HIM OR BY THE IMPORTANCE OF THE KNOWLEDGE TO BE GAINED," AND THAT INFORMED CONSENT IS OBTAINED.

EACH INSTITUTION MUST SUBMIT TO DHEW AN ASSURANCE OF COMPLIANCE WITH THE POLICY; THUS, INSTITUTIONS WERE ASKED TO POLICE THEMSELVES.

THE NATIONAL RESEARCH ACT ALSO CREATED THE NATIONAL COMMISSION FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH. THIS COMMISSION IS RESPONSIBLE FOR:

1. DEVELOPING GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS AND THE BOUNDARIES BETWEEN RESEARCH AND ROUTINE PRACTICE;
2. DEVELOPING RISK/BENEFIT CRITERIA AND ASSESSMENT;
3. CREATING GUIDELINES FOR THE SELECTION OF SUBJECTS;

4. DEFINING THE NATURE OF INFORMED CONSENT
IN VARIOUS RESEARCH SETTINGS; AND
5. DEVELOPING MECHANISMS FOR MONITORING
AND EVALUATING THE PERFORMANCE OF
INSTITUTIONAL REVIEW BOARDS.

ON JANUARY 12, 1978, THE COMMISSION PUBLISHED ITS REPORT AND RECOMMENDATIONS REGARDING RESEARCH WITH CHILDREN IN THE FEDERAL REGISTER. THIS REPORT, ALTHOUGH BASED ON TESTIMONY AND SURVEYS BASICALLY CONDUCTED IN AREAS OTHER THAN EDUCATIONAL RESEARCH (e. g., MEDICAL RESEARCH AND PSYCHOLOGICAL RESEARCH), HAS BROAD RAMIFICATIONS FOR THE MANNER IN WHICH EDUCATIONAL RESEARCH MAY BE CONDUCTED. FOR EXAMPLE, FOR ALL RESEARCH INVOLVING "MINIMAL RISK" WITH CHILDREN OVER THE AGE OF 7, BOTH THE ASSENT OF THE CHILD AND THE PERMISSION OF THE PARENT OR GUARDIAN WILL BE REQUIRED. "MINIMAL RISK" IS DEFINED BY THE COMMISSION AS "THE PROBABILITY AND MAGNITUDE OF PHYSICAL OR PSYCHOLOGICAL HARM THAT IS NORMALLY ENCOUNTERED IN THE

DAILY LIVES, OR IN THE ROUTINE MEDICAL OR PSYCHOLOGICAL EXAMINATION, OF HEALTHY CHILDREN." THESE CONSENT PROCEDURES MUST MEET THE SPECIFICATIONS OF "INFORMED CONSENT." COMMENTS ON THE RECOMMENDATIONS WERE ACCEPTED UNTIL MARCH 14, 1978.

THE HIGHLIGHTS PRESENTED ON THE FOUR MAJOR PIECES OF LEGISLATION AND CURRENT EFFECTS CAN, AT BEST, ILLUSTRATE THE IMPACT OF THE INVOLVEMENT OF THE FEDERAL GOVERNMENT IN REGULATING THE COLLECTION, MAINTENANCE AND RELEASE OF RECORDS USED BY OR FUNDED BY A FEDERAL AGENCY. HIGHER COSTS, GREATER CONTROL AND INCREASED PAPERWORK ARE BUT THREE OF THE MORE OBVIOUS ISSUES. MORE IMPORTANTLY, IS THE IMPACT ON THE QUALITY OF THE EDUCATIONAL RESEARCH WHICH CAN BE CONDUCTED. PROFESSIONAL AND ETHICAL RESPONSIBILITIES REQUIRE FURTHER CONSIDERATION OF THIS MATTER BY EDUCATIONAL RESEARCHERS INDIVIDUALLY AND ASSOCIATIONALLY, NOT JUST IN RESPONSE TO FEDERAL STRICTURES, BUT AS EVIDENCE OF THEIR CONCERN.
